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Peer comment for „Addressing Consent Issues in Donation after Circulatory Determination of Death"

Resolving some, but not all informed consent issues in DCDD – the Swiss experiences

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We fully agree with Overby and colleagues that donation after circulatory determination of death (DCDD) poses special problems that need to be addressed in the consent procedure (Bastami et al. 2012). In our comment, we want to refer to the Swiss experiences related to DCDD that are able to overcome some, but not all concerns made by the authors. Those concerns refer to the issues of pre-mortem interventions, the potentially questionable irreversible loss of brain functions and the challenge of making an adequate prognosis in certain patient (we will not discuss the last point).

Swiss transplantation centers have a considerable long experience with DCDD starting in the 1980s. When the first national law regarding transplantation came into effect in 2007, DCDD was stopped for four years – interestingly due to informed consent issues, because usually close relatives have been asked to consent to donation before the death of the patient has occurred, which was considered to be potentially incompatible with the new legislation. Further legal refinement was needed until the practice of DCDD was finally considered to be legal. In October 2011 DCDD was restarted – mainly in the University Hospital Zurich and only as controlled DCDD – and now accounts for 10.9% of all donations in Switzerland (data of 2013).

However, there is a unique feature ever since DCDD has been practiced in Switzerland:[1] it requires a neurological determination of death after a 10 minutes no-touch period. This brain death diagnosis involves all standard neurological tests except the apnea test (which makes no sense as the patient is no more ventilated anyway) and testing the vestibule-ocular reflex where stimulation is based on pouring of cold or warm water into the ear. Performing the tests usually takes an additional 1-3 minutes, meaning that warm ischemic time is in the order of 11-13 minutes after cessation of death. In Zurich, data collected in the first period of DCDD show no significant difference in long-term rate of graft survival in case of kidneys when comparing with kidneys obtained after "standard" brain death (Weber et al. 2002). Data regarding liver and lung are preliminary, since DCDD for both organs have only started in 2011. However, preliminary results indicate that the short term outcome for lungs is at least as good as for donation after brain death. And although the liver seems to be more vulnerable to the longer ischemia time associated with DCDD, the use of hypothermic oxygenated perfusion (HOPE) seems to improve early function after transplantation and the release of liver enzymes and kidney function as well as ICU and hospital stays were comparable or better than in matched liver grafts emerging from donation after brain death (DBD); but if long-term results are the same or worse than in DBD cannot be evaluated so far (Dutkowski et al. 2014). Nevertheless, the Zurich experiences indicate that integrating a brain death diagnosis in DCDD is compatible with an acceptable success rate for DCDD in case of kidneys, and maybe also for other organs.

[1] In November 2013, Austria has changed DCDD protocols and also requires the determination of brain death after a 10 minutes no-touch period.

So far, following this practice in Switzerland, brain death has always been confirmed after the 10 minutes no-touch period – which is by the way twice as much as the standard 5 minutes in most other international centers that practice DCDD. To our understanding, this relieves the second concern of Overby and colleagues, namely that DCDD practices may not ensure irreversible loss of brain function.[2] Furthermore, by explicitly including a brain death diagnosis procedure in DCDD, patients are likely to have more trust in the procedure as such and obtaining informed consent will be less challenging as the analogy to "classic" organ donation is closer.

Nevertheless, pre-mortem interventions remain a sensible ethical issue also in the Swiss context. An empirical study by one of us evaluating experiences of relatives of donors after DCDD compared to DBD demonstrate that the type of donation did not remain prominently in the memory of DCDD donor relatives (Bastami 2014). Whether this is due to a lack of information at the time of donation, the extreme stress situation in which relatives find themselves and the complexity of DCDD donation, or whether the distinction is not important to them remains the subject of future research. Interestingly, it was found that DBD donor families may find the concept of brain death difficult and sometimes suffer from guilt because of what they perceive as their role in their loved one's death, whereas DCDD donor relatives did not mention any such feelings.

More careful communication with patients and relatives, however, has led to increased acknowledgment of the special aspects related to DCDD in particular regarding pre-mortem interventions. Also regarding transplantation in general, the wish of family members to hear about the success of donation is acknowledged. Nowadays, in Zurich, transplant coordinators stay in touch with donor families and conduct a follow-up interview with them several months after donation. Also "Swisstransplant", the Swiss organ procurement organization (OPO), now informs about the special procedures associated with DCDD. Furthermore, the pre-mortal placement of catheters – probably the most invasive procedure related to DCDD – is not part of the current Swiss practice focusing on Maastricht 3 donation. This demonstrates that DCDD practice and the informed consent procedure indeed can be improved.

Despite these measures, our findings support the observation of Overby and colleagues that still much needs to be done, in particular related to the information of potential donors by Organ Procurement Organizations and similar institutions. In an ongoing study, we are currently assessing the international information practice related to DCDD by such organizations. Still very preliminary results show that 23 out of 38 websites of OPOs worldwide (61%) do not even mention that DCDD may be the way donation actually could take place in a person that registers as donor; and only 5 websites (13%) provide detailed information on the particularities of DCDD. This indicates a substantial "information gap" that needs to be addressed.

In summary, we believe that the Swiss experiences allow improving the informed consent practice and the procedures related to DCDD in general by the following means: First, by including a brain death diagnosis into the DCDD practice, both trust of the donor as well as the analogy to "classical" organ donation can be strengthen. Second, by carefully communicating the particular aspects of DCDD to close relatives of a potential donor (that in most cases actually decide upon donation), improving informed decision making can be expected. Third, by abandoning the most problematic practices related to pre-mortem interventions, the ethical difficult issues related to DCDD can be at least partly relieved. However, as our ongoing study shows, there is still much to be done for improving

[2] We note that the neurological determination of death may not in all cases demonstrate an irreversible loss of brain functions (see, e.g., Joffe et al. 2009, Webb & Samuels 2011, these findings have been controversially discussed) and that in some cases a cardiorespiratory arrest of more than 10 minutes still allows for neurological recovery of patients (Machado & Korein 2009). However, the patients that qualify for controlled DCDD are very unlikely to fall into these categories.

general information on DCDD in particular for those persons that want to disclose their wish regarding donation in registries.

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